



# Agent Orange Brief

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## AGENT ORANGE AND SPINA BIFIDA

### **What is spina bifida? Why are Vietnam veterans concerned about it?**

Spina bifida is the most frequently occurring permanently disabling birth defect. It affects approximately one of every 1,000 newborns in the United States. Neural tube defects (NTD) are birth defects that involve incomplete development of the brain, spinal cord, and/or protective coverings for these organs. Spina bifida, the most common type of NTD, results from the failure of the bony spine to close properly during the first month of pregnancy. (Anencephaly and encephalocele are less common types of NTDs). In severe cases of spina bifida, the spinal cord protrudes through the back and may be covered by skin or a thin membrane.

Some Vietnam veterans have children with spina bifida. While Vietnam veterans are now moving out of the age category usually associated with childbirth, it is anticipated that some future births will occur and that some of these children may have birth defects, including spina bifida. Some research efforts have suggested that there may be a relationship between exposure by Vietnam veterans to Agent Orange and/or other herbicides used in Vietnam and the subsequent development of spina bifida in some of their children.

### **What can be done for children with spina bifida?**

Surgery to close the infant's back is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord. Because of the paralysis resulting from the damage to the spinal cord, people born with spina bifida may need surgeries and other extensive medical care. Spina bifida is also associated with bowel and bladder complications.

Many individuals with spina bifida also suffer with hydrocephalus, fluid in the brain. Hydrocephalus is controlled by a surgical procedure, which relieves the fluid build up by redirecting it to the abdominal area.

Because of medical advances, most children born with spina bifida live well into adulthood.

**What did the National Academy of Sciences (NAS) conclude about the relationship between exposure to herbicides and the development of spina**

**bifida in its 1993 report, entitled Veterans and Agent Orange - Health Effects of Herbicides Used in Vietnam?**

While there were several references to spina bifida in this 832-page report, the condition was grouped with all other birth defects. The NAS reviewers concluded that there is "inadequate or insufficient evidence" to determine whether an association exists between exposure to herbicides used in Vietnam and birth defects among offspring.

**What did the 1996 NAS update conclude about spina bifida?**

In 1996, the NAS commented that published results of the analysis of birth defects among the offspring of the Operation Ranch Hand (the Air Force unit responsible for most of the Agent Orange spraying) personnel "suggest the possibility of an association between dioxin exposure and risk of neural tube defects."

The NAS reviewers noted that a number of studies of veterans "appear to show an elevated relative risk for either service in Vietnam or estimated exposure to herbicides or dioxin and neural tube defects (anencephaly and/or spina bifida) in their offspring."

NAS noted that while the Centers for Disease Control (CDC) Birth Defects Study revealed no association between "overall Vietnam veteran status" and the risk of spina bifida or anencephaly, the CDC herbicide "exposure opportunity index," based on interview data, indicated an increased risk of spina bifida in the children of Vietnam veterans who had high index ratings. There was no similar pattern of association for anencephaly.

The CDC Vietnam Experience Study indicated that more Vietnam veterans reported that their children had a central nervous system disorder (including spina bifida) than did non-Vietnam veterans who participated in the study.

The NAS observed that all three of these epidemiologic studies (which are of the "highest overall quality") suggest an association between herbicide exposure and an increased risk of spina bifida in offspring. While the NAS took note of the weaknesses in each of these studies, the NAS report concluded that there is "limited/suggestive evidence" of an association between exposure to herbicides used in Vietnam and spina bifida. On the other hand, the NAS found "inadequate or insufficient evidence to determine whether an association exists" between exposure to the herbicides and "all other birth defects."

**What was VA's response to the NAS finding regarding spina bifida?**

While Secretary Brown could easily add peripheral neuropathy and prostate cancer (two other "limited/suggestive evidence" conditions cited in the 1996 update) to the list of conditions recognized by VA for presumption of service connection for Vietnam veterans based on exposure to herbicides, VA lacked the authority to provide benefits to non-veterans based on the possible relationship between those individuals' disabilities and a veteran's service.

On May 28, 1996, President Clinton announced that VA would send to Congress proposed legislation that would provide an "appropriate remedy" for Vietnam veterans' children who suffer from spina bifida. On July 25, 1996, Secretary Brown sent to Congress a draft bill that would provide for the special needs of these children through the provision of comprehensive medical care, vocational training, and monetary benefits (monthly allowance). On July 28, 1996, the legislation was introduced in the Senate and House of Representatives. In September, Congress approved a similar version of the spina bifida legislation with an effective date of October 1, 1997, as part of the VA FY1997 appropriations bill. It became Public Law 104-204 on September 26, 1996, when it was signed by President Clinton.

In May 1997, proposed rules regarding monetary allowance and healthcare for Vietnam veterans' children with spina bifida were published in the Federal Register. (See 62 Fed. Reg. 23724 and 23731, May 1, 1997). In July 1997, the proposed rule regarding vocational training and rehabilitation for Vietnam veterans children with spina bifida was published in the Federal Register. (See 62 Fed. Reg. 35454, July 1, 1997). The three final rules, effective October 1, 1997, were published in the Federal Register in September 1997. (See 62 Fed. Reg. 51274, 51281, and 51286, September 30, 1997).

On May 24, 1996, VA announced a "solicitation for applicant to establish a research center for epidemiological, clinical, and basic science studies of environmental hazards and their effects on reproductive and developmental outcomes." On November 14, 1996, VA announced that the Louisville VA Medical Center was selected as the site of this center.

**What benefits/services are now available for Vietnam veterans' children with spina bifida?**

**Monetary allowance.** Public Law 104-204 provides that the monthly monetary allowance for any Vietnam veteran's child with spina bifida be based on the degree of disability suffered by the child. The law required VA to establish three levels of disability for this allowance. Under the final regulations, the stipend or monthly monetary allowance ranges from \$200 to \$1,200, based on the degree of disability suffered by the child. This allowance is subject to annual cost-of-living increases and will not be counted as income in any federal means-tested programs. Vietnam veterans' children are eligible for the monthly allowance throughout their lives, regardless of their age or marital status.

VA regulations defined the three levels of disability as follows:

For Level I, the least severe level of disability, the child is able to walk without braces or other external support, has no sensory or motor impairment of arms, has an intelligence quotient (I.Q.) of 90 or higher, and is continent of urine and feces. The monthly allowance is \$200;

For Level II, the intermediate level, none of the child's disabilities are severe enough to be evaluated at Level III, and the child can walk, but only with braces or other external support, or has sensory or motor impairment of arms, but is able to grasp a pen, feed him or herself, and

perform self care, or has an I.Q. of at least 70 but less than 90, or requires drugs or intermittent catheterization or other mechanical means to maintain proper bowel function. The monthly allowance is \$700; and

For Level III, the most severe level, the child is unable to walk or has sensory or motor impairment severe enough to prevent grasping a pen, feeding self, and performing self care, or has an I.Q. of 69 or less, or has complete urinary or fecal incontinence. The monthly allowance is \$1,200.

A child who meets any one of the criteria in a level is rated at that level. For example, a child who meets all the criteria for level one, but who has total incontinence (Level III criteria) will be rated and paid at Level III.

As of January 20, 1999, VA is providing benefits to 739 children under this program. Of these 739, 48 (6 percent) are at Level I, 184 (25 percent) are at Level II, and 507 (69 percent) are at Level III.

**Health Care.** Under the final rule for health care, VA provides Vietnam veterans' children who are suffering from spina bifida with health care services VA determines are needed for the spina bifida or any disability that is associated with spina bifida. This is not intended to be a comprehensive insurance plan and does not cover health care unrelated to spina bifida.

Under this final rule, health care may be provided directly by VA, by contract with an approved health care provider, or by other arrangements with an approved health care provider. VA may inform spina bifida patients, parents, or guardians that health care may be available at not-for-profit charitable corporations (such as Shriners hospitals) for children under age 18.

In March 1997, VA and Shriners Hospitals for Children (SHC) reached an agreement for SHC to care for Vietnam veterans' children with spina bifida at no charge for outpatient or inpatient care for children up to the age of 18 with this condition. VA reimburses non-SHC facilities providing care to children older than 18 and those whose parents or guardians choose not to receive their care at SHC.

VA also reimburses non-SHC facilities for necessary medical services not offered by SHC and covers transportation costs for patients and their parent or legal guardian to an SHC unit or any outside facility required for treatment of the patient. SHC currently treats about 5,000 children with spina bifida, the largest number of such patients treated by any hospital system in the world.

**Vocational Training and Rehabilitation.** VA provides an evaluation to a Vietnam veteran's child who VA has determined suffers from spina bifida. If this evaluation establishes that it is feasible for the child to achieve a vocational goal, VA will provide the child with the vocational training, employment assistance, and other related rehabilitation services that VA finds the child needs to enable the child to achieve a vocational goal, including employment.

Vocational training program for a child with spina bifida must consist of such vocationally oriented services and assistance, including such placement and post-placement services and personal and work adjustment training, as VA determines are necessary to enable the child to prepare for and participate in vocational training and employment.

Training may include a program of education at an institution of higher education if VA determines that the program of education is predominately vocational in content.

**What did the NAS conclude about spina bifida in its 1998 update?**

The 1998 report concludes that new occupational studies (Canadian farmers/Norwegian farmers and a case control study of parental occupation and spina bifida incidence in the Netherlands) all indicate a higher incidence of this condition among the children of males exposed to herbicides/pesticides.

**Where and how does someone get these benefits and services?**

Approval of monetary support, health care, and vocational training is based on eligibility determinations made at VA regional benefit offices. Prospective beneficiaries must first complete an application for benefits. They should contact the nearest VA regional office toll-free at 1-800-827-1000.

**Where can a veteran get additional information about spina bifida?**

Some information regarding spina bifida and related matters can be obtained at VA medical center libraries, in other medical libraries, from the Registry Physicians at every VA medical center, or from the Environmental Agents Service (131), Department of Veterans Affairs, 810 Vermont Avenue, N.W., Washington, DC 20420. Non-government organizations, such as the Spina Bifida Association of America (SBAA), Easter Seal Society, and the March of Dimes, also have a great deal of information. The SBAA is located at 4590 MacArthur Blvd., Suite 250, Washington, DC 20007-4226. The toll-free telephone number for SBAA is (800) 621-3141. The e-mail address is spinabifda@aol.com.